



## The NCI-Ireland Consortium: A Unique International Partnership in Cancer Care

PATRICK G. JOHNSTON,<sup>a</sup> PETER A. DALY<sup>b</sup>

<sup>a</sup>Department of Oncology, Queen's University Belfast, Belfast, Northern Ireland; <sup>b</sup>St. James's Hospital, Dublin, Ireland

### ABSTRACT

The Ireland-Northern Ireland-National Cancer Institute Cancer Consortium was launched in October of 1999, at a conference in Belfast, Northern Ireland, for the development of cancer programs in Ireland and Northern Ireland, where cancer is a significant cause of mortality and morbidity.

Cancer services there have undergone major restructuring as a result of several government reports. Specifically, the National Strategy Document for Cancer proposed that cancer treatment services should be centered around primary care services, regional services, and a national coordinating structure where supra-regional centers would deliver specialist surgery, medical and radiation oncology, rehabilitation, and specialist palliative care. Therefore, this was an opportune time to bring the National Cancer Institute (NCI) on board in a determined effort to redevelop and significantly improve services and outcomes for cancer patients throughout the island.

During the NCI All Ireland Cancer Consortium, initial major goals were established as follows: A) To

share best available technology and enhance clinical research; B) conduct joint clinical research studies involving people from all jurisdictions; C) sponsor formal training exchanges for Irish and American scholars in cancer programs in partner institutions; D) implement the use of teleconferencing, telesynergy, and other information technology capabilities to facilitate education, and E) consolidate the Cancer Registries of Ireland and Northern Ireland and learn more about cancer incidence and trends on the entire island. In the past year, significant advances have been made in all these areas.

Plans are already under way for the second NCI All Ireland Cancer Conference which will be held in late 2002 and feature speakers from Ireland, Northern Ireland, the U.S., and other areas. It will be open to all oncologists, researchers, nurses, students, and other health care professionals interested in learning and enhancing cancer care and research. *The Oncologist* 2001;6:453-458

### INTRODUCTION

In October 1999, over 700 oncologists, scientists, nurses, and government health officials from Ireland, Northern Ireland, the U.S., and elsewhere convened in Belfast, Northern Ireland, to attend a 3-day conference and participate in the launch of the Ireland-Northern Ireland-National Cancer Institute (NCI) Cancer Consortium. The Conference opened with the signing of an historic

Memorandum of Understanding between the Departments of Health and Children of Ireland, Department of Health and Social Services, Northern Ireland, and the NCI of the U.S. Department of Health and Human Services at Stormont Parliament Buildings where political representatives and conference attendees gathered to witness this very important event. The conference itself was the initial manifestation of a multilateral partnership to forge strategic alliances among

Correspondence: Patrick G. Johnston, M.D., Ph.D., FRCP, FRCPI, Department of Oncology, Queen's University Belfast, University Floor, Belfast City Hospital, Belfast BT9 7AB, Northern Ireland. Telephone: 44-028-90-263911; Fax: 44-028-90-263744; e-mail: p.johnston@qub.ac.uk Received June 1, 2001; accepted for publication July 6, 2001. ©AlphaMed Press 1083-7159/2001/\$5.00/0

the three jurisdictions, to improve clinical cancer services and patient care on the island of Ireland, and to foster joint collaboration in cancer research and development. This decision by the NCI to develop an NCI All Ireland Agreement for Cancer Research and Clinical Development on the island of Ireland was a major boost for the developing cancer programs in Ireland and Northern Ireland.

#### THE CANCER PROBLEM ON THE ISLAND OF IRELAND

Cancer is a significant cause of mortality and morbidity in Ireland and Northern Ireland today. Approximately 25,200 new cases of cancer are diagnosed per year and 11,000 people die each year from the disease (Tables 1 and 2). Cancer rates are higher in males (12,967/year) than females (12,233/year). Non-melanoma skin cancer is the most frequent cancer in both sexes (30% in all cases), with lung and related cancers second overall (10% of cases). Breast cancer is the second most frequent in females (19% of cases) and prostate cancer is second in males (12% of cases). Each year 5,869 men and 5,118 women die from cancer. Lung and related cancers are the most frequent causes of cancer death, accounting for 22% of all cancer deaths while in

men, lung cancer accounts for 27% of deaths. Breast cancer is the third most frequent category overall for both incidence and mortality, and colorectal cancer is the fourth most frequent cancer overall, accounting for 7% of incident cases and 9% of cancer deaths. On average females are estimated to have a 30% (1 in 3.3) chance of developing cancer by age 74, and males a 36% (1 in 3) chance. Females have an estimated 12%-13% (1 in 8) chance and males have a 17% (1 in 6) chance of dying from this disease. Therefore, within the Western World, the island of Ireland has a very high cancer incidence and mortality rate (Fig. 1).

#### CANCER SERVICES IN IRELAND

Over the last several years there has been a major restructuring of cancer services in both Northern Ireland and Ireland as a result of several government reports, including the Campbell Report in Northern Ireland and the National Strategy Document for Cancer in Ireland. In Ireland, the National Strategy Document proposed that cancer treatment services should be centered around primary care services, regional services, and a National Coordinating Structure where supraregional centers would deliver specialist surgery,

**Table 1.** Summary statistics, all Ireland 1994-1996: all malignant cancers

	New cases		Deaths	
	Females	Males	Females	Males
Cases per year	12,233	12,967	5,118	5,869
% of total	100.0	100.0	100.0	100.0
Cumulative risk (0-74 years) %	29.6	36.1	12.4	17.2
<b>Rates per 100,000 per year (<math>\pm 95\%</math> conf. limits):</b>				
Crude rate	460.0	499.0	192.5	225.8
World age-standardized rate	311.3 ( $\pm 3.5$ )	385.3 ( $\pm 3.9$ )	116.6 ( $\pm 2.0$ )	168.6 ( $\pm 2.6$ )
European age-standardized rate	442.5 ( $\pm 4.7$ )	573.2 ( $\pm 5.7$ )	174.0 ( $\pm 2.9$ )	260.0 ( $\pm 3.9$ )
Mortality/incidence ratio	0.42	0.45	–	–

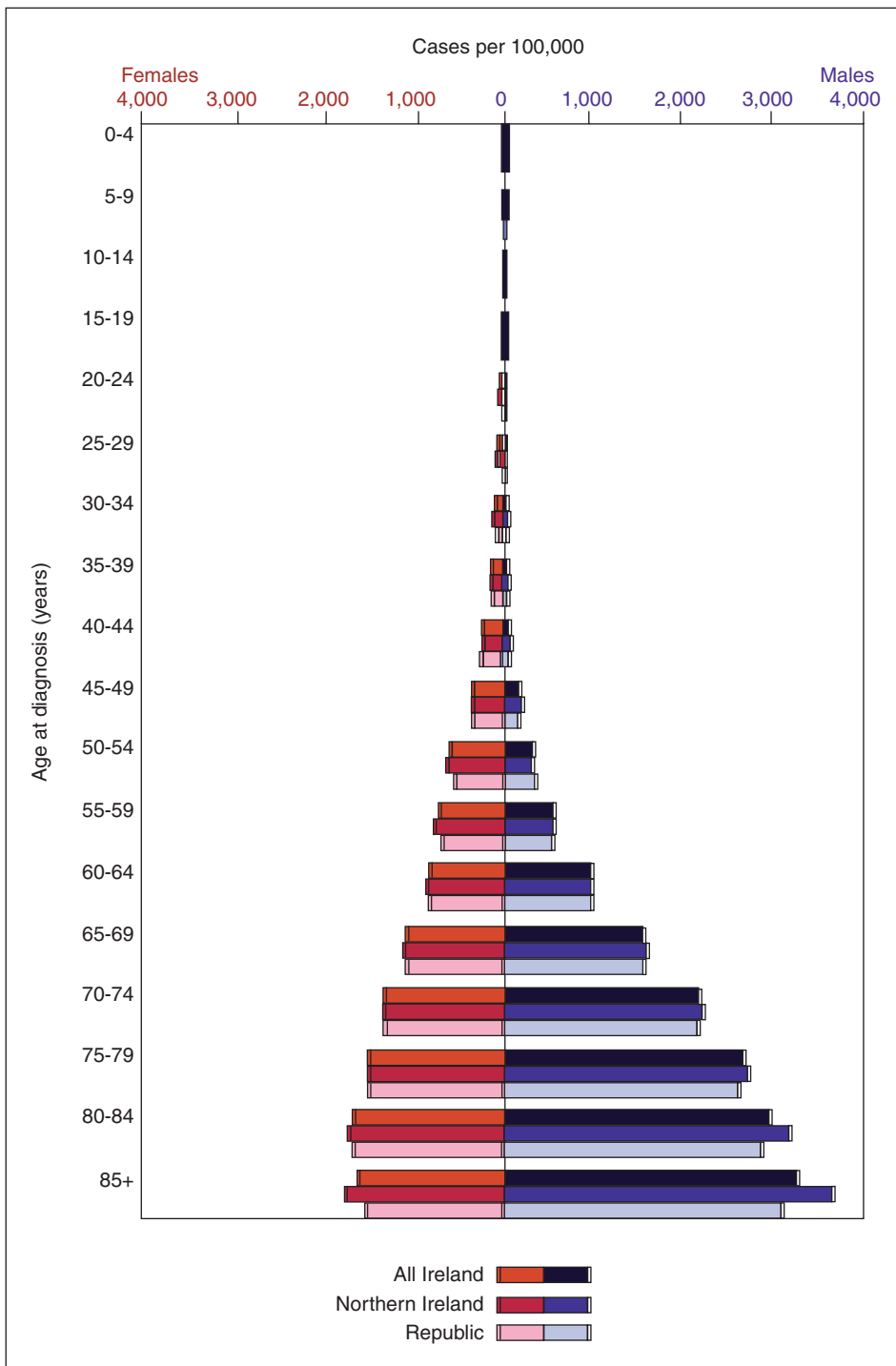
**Table 2.** Summary statistics, all Ireland 1994-1996: all malignant cancers, excluding non-melanoma skin cancer

	New cases		Deaths	
	Females	Males	Females	Males
Cases per year	8,787	9,077	5,108	5,839
% of total	71.8	70.0	99.8	99.5
Cumulative risk (0-74 years) %	23.2	27.2	12.4	17.1
<b>Rates per 100,000 per year (<math>\pm 95\%</math> conf. limits):</b>				
Crude rate	330.4	349.3	192.1	224.7
World age-standardized rate	232.5 ( $\pm 3.0$ )	270.8 ( $\pm 3.3$ )	116.6 ( $\pm 2.0$ )	167.8 ( $\pm 2.6$ )
European age-standardized rate	325.1 ( $\pm 4.1$ )	399.4 ( $\pm 4.8$ )	173.7 ( $\pm 2.9$ )	258.6 ( $\pm 3.9$ )
Mortality/incidence ratio	0.58	0.64	–	–

*Figure 1. Average annual age-specific incidence rates (per 100,000) for all Ireland, Northern Ireland and Republic of Ireland, 1994-1996: all malignant cancers excluding non-melanoma skin cancer (NMS). Age-profiles for cases including NMS were broadly similar.*

medical and radiation oncology, rehabilitation and specialist palliative care. Currently supraregional cancer centers are being established in the cities of Dublin, Cork, and Galway, and a National Cancer Forum, which has served as a multidisciplinary advisory board to the Department of Health and Children, has pushed the development and implementation of this plan forward. In Northern Ireland the Chief Medical Officer published a report entitled "Cancer Services—Investing for the Future." Key recommendations were that Northern Ireland should have one cancer center in Belfast and four smaller cancer units. This report also highlighted that this cancer center should be one that would contain surgical, medical, and radiation oncology facilities, develop specialist palliative care, and have an ethos of research and development at its core. The report went on to recommend the implementation of multidisciplinary teams as part of the approach to cancer diagnosis, treatment, and palliative care and set clear guidelines and key targets for patients accessing cancer services.

In both parts of the island the recommendations of these reports have been accepted and are currently being implemented. Therefore, structured redevelopment of cancer services for patients has been and continues to be a top priority for both Departments of Health. This is, then, an opportune time to bring the expertise of the NCI on board in a determined effort to redevelop and significantly improve services and outcomes for cancer sufferers throughout the island.



**THE NCI ALL IRELAND CANCER CONSORTIUM’S PROGRESS TO DATE**

During the NCI All Ireland Conference all were conscious that this was just a starting point. The need for further intense activity and collaboration in cancer research and service development was recognized and at the close of the conference several working groups were formed to develop initial action plans for this unique international partnership. Initial major goals were:

- to share the best available technology and enhance clinical research;
- to conduct joint clinical research studies involving people from all three jurisdictions;
- to sponsor formal training exchanges for Irish and American scholars in cancer programs in partner institutions;
- to implement the use of teleconferencing, telesynergy, and other information technology capabilities to facilitate education, and
- to consolidate the Cancer Registries of Ireland and Northern Ireland and learn more about cancer incidence and trends on the entire island.

At the conference, it was also decided to set up a governance board of directors to administer the Consortium. This board is now formed and comprises the chief medical officers of Ireland and Northern Ireland, and the Director of the NCI. They meet twice a year to evaluate proposals and determine the Consortium's scope of activities. The Consortium board has also established an implementation group representing the Ministries of Health in Northern Ireland and Ireland and the NCI. The function of the implementation group is to receive and review proposals on behalf of the board and to coordinate the implementation of those programs supported by the board.

Over the last 12 months there have been significant developments within each of the key areas outlined. The Consortium has built significantly upon the enthusiasm generated during the NCI All Ireland Cancer Conference and made much progress toward developing joint programs in scholarship exchange, cancer registration, information technology, and clinical trials in its effort to advance cancer care and research. The progress in each of these areas is as follows.

#### **EDUCATION—SCHOLARSHIP EXCHANGE AND TRAINING**

Education formed one of the major platforms of the initiative. Through the work of the Consortium, educational programs and research training opportunities for nurses and medical and scientific fellows are now being provided. The purpose of the scholarship exchange programs is to accelerate training and increase the number of skilled medical, radiation, and surgical oncologists, research nurses, scientists, and other cancer professionals on the island of Ireland. Through these programs scholars in Ireland and Northern Ireland have the opportunity to undertake a portion of their education at the NCI or affiliated institutions by competing

for Consortium fellowships. Scholars may also participate in short-term (3- to 6-month) training programs to round out their education or enhance particular skills. Long-distance learning opportunities such as videoconferencing are currently being developed, and scholarship exchange opportunities will also exist in the future for U.S. scholars to study at designated sites in Ireland and Northern Ireland. Already the first Fellows to participate in a Consortium scholarship exchange program, *Dr. Paul Walsh* (Ireland) and *Dr. Peter McCarron* (Northern Ireland), have begun a 3-year fellowship in epidemiology, 1 year of which is spent at the NCI developing research programs that will be continued in their home countries. Both scholars began their fellowships in cancer epidemiology in January 2001 after competing successfully among 40 applicants from Ireland and Northern Ireland Summer fellowships. In addition, training programs for medical and radiation oncologists are currently being developed with links to existing programs within the NCI. Nurses have also begun to develop joint training areas in clinical trials research, clinical oncology nurse training, pre-doctoral fellowship programs, as well as NCI summer curriculum programs in cancer genetics and prevention. Indeed 12 fellows have already been accepted for these summer programs beginning in July 2001. These exchanges will involve not only the NCI but also leading cancer institutions in Northern Ireland and Ireland, and will enhance the breadth of skills of health professionals involved in cancer care and cancer research.

#### **TELECOMMUNICATIONS AND INFORMATION TECHNOLOGY**

Teleconferencing and information technology facilities are already well developed in Ireland, Northern Ireland, and at the NCI. However, further investment in infrastructure and core development will be vital to underpin major elements of the partnership. Through the Consortium several necessary enhancements of the informatic infrastructure are being made to support coordinated clinical trials and to facilitate cross-border and Transatlantic learning and education. Two initial programs are currently under way.

##### **Telecommunications**

The NCI telesynergy system has been installed in St Luke's Hospital in Dublin and is currently being purchased for the Northern Ireland Cancer Center at Belfast City Hospital. Telesynergy is a medical imaging workstation allowing partnering institutions to conduct consultation, training, and off-site research through simultaneous high-resolution display of medical images. Telesynergy allows remote consultations and education between geographically disparate medical specialties of all types and does

this without the constraints of time or travel. This system will enable the partners to communicate and collaborate effectively.

#### **Clinical Trial Information System (NET-Trials)**

The second major program under way is the development of the NET-Trials. Belfast City Hospital and other hospitals in Ireland are now equipped, and the staff have been or are being trained in the NCI's NET-Trial System. This provides a uniform means of recording and analyzing patient information related to clinical trials, and provides an information framework for collaborative clinical investigations among the three countries. The system will allow phase I and phase II clinical research trials to be conducted beyond the Bethesda campus and allows patient protocol information to be directly entered into the NCI database. It will also act as a prototype for clinical research and treatment conducted by electronic means. The initial NET-Trial system is now operational at Belfast City Hospital and patient data are already being entered onto this system.

#### **CLINICAL TRIALS**

A major goal for the Consortium was to strengthen the capacity for cancer centers in Ireland and Northern Ireland to conduct cancer clinical trials and to enhance opportunities for patients to participate in trials as a way of improving cancer care and reducing cancer mortality throughout the island. The modernization of cancer care requires placing delivery of care in the context of evidence-based medicine and requires a vigorous and contemporary clinical trials infrastructure centered around the clinical trials (NET-Trials) system already outlined. The Consortium has now agreed upon a process toward establishing a network of hospitals within Ireland and Northern Ireland that will participate in clinical trials. The Irish Clinical Oncology Research Group will be the coordinating body with offices in Dublin and Belfast. This network, currently being developed, will be modeled on the Co-operative Clinical Trials Groups, which conduct trials in the U.S. from multiple locations. The NET-Trials system will enable the provision of a uniform system for recording and analyzing patient information and will provide the institutions involved with systems that are compatible for data collation, analysis, and presentation with studies performed at the NCI. Moreover, the system will allow participating centers to immediately conform to international standards, and this should inevitably result in further significant improvements in cancer care.

#### **CANCER REGISTRIES POPULATION STUDIES**

A very significant area of collaboration and partnership has been between the Cancer Tumor Registries in both

Northern Ireland and Ireland. The monitoring of improvements in cancer care can only be undertaken with reliable tumor registry information. This is now available in both Northern Ireland and Ireland and both Ministries of Health recognize the importance of this process. Through the Consortium a long-term initiative has been established to consolidate data from the Northern Ireland Cancer Registry and the National Cancer Registry of Ireland. The National Cancer Institute has proposed to assist both Registries with developing a common database that can assist with consultation, informatic tools, and quality control. Moreover, joint programs will help researchers understand more about cancer rates, trends, and outcomes on the entire island by identifying geographic and population differences in cancer patterns and studying possible links between cancer incidence and occupations on the environment and lifestyle influences. As part of this development the Consortium has awarded its first fellowships in cancer epidemiology to *Dr. Peter McCarron* (Northern Ireland) and *Dr. Paul Walsh* (Ireland) who are linked to the Cancer Registries.

The second major initiative in this area has been the publication of the first All Ireland Cancer Incidence Report, which is a joint effort by the Northern Ireland Cancer Registry and the National Cancer Registry of Ireland. This report was released in May 2001 at the most recent Consortium Board meeting. The report outlined the cancer problem in terms of cancer incidence and mortality, as well as highlighted trends and outcomes on the entire island. This is the first collaborative report of the two Cancer Registries and the first jointly produced product delivered by the Consortium. This consolidation of the Cancer Registries will improve the overall quality of data collection and provide information on a genetically stable population. It will, therefore, become a major tool for future epidemiological investigations and service developments.

#### **WEBSITE AND HELP DESK**

The Cancer Consortium's website was also recently launched in May 2001. This provides comprehensive information. Oncologists, scientists, nurses, students, and others can check out training and education programs of interest available through the Consortium and access the Consortium Help Desk to be connected with program administrators. The Website also contains downloadable documents such as the recent All Ireland Cancer Incidence Report, video footage as well as news items on future meetings and events. Access to current and accurate cancer information for the general public is also possible through the NCI's cancer net website. The website address is <http://www.allirelandnci.com>.

**FUTURE PLANS**

Since the signing of the Memorandum of Understanding in October 1999, the Consortium has begun to achieve several of its major objectives. There are already in place the first tangible accomplishments in several major areas including scholarship exchange, telecommunication linkages, and the joint report from the Cancer Registries. The next steps in this process will be to expand awareness of the activities of the Consortium and the opportunities available. It will be necessary to continue to build the infrastructure to accomplish the Consortium's goals and to expand trained staff through scholarship exchange training sessions and recruitment. Plans are already under way for the second NCI All Ireland Cancer Conference, which will be held in Ireland in late 2002. The Conference will again feature speakers from Ireland, Northern Ireland, the U.S., and elsewhere, and will be open to oncologists, researchers, nurses, students, and other health care professionals with an interest in learning about and enhancing cancer care and research. There is no doubt that the NCI All Ireland Agreement has already begun to speed up the process of cancer development on the island of Ireland and also has become a major milestone agreement for international cancer care. The Consortium has successfully begun to join both jurisdictions with the U.S. in a quest toward improved cancer care and treatment for

our people and in the process has fostered improved relations. We look forward to further successes and increasing collaboration as part of this important international partnership. Already cancer patients and their families on the island of Ireland are beginning to benefit from this initiative.

**Patrick G. Johnston, M.D., Ph.D.**

Queen's University Belfast  
Belfast, Northern Ireland

**Peter A. Daly, M.D.**

St. James's Hospital  
Dublin, Ireland

